



# Autism Society of NORTH CAROLINA

## Guardianship

### Considering Guardianship Issues

Parents of a child with autism may struggle with questions about how to best protect their child as he grows into adulthood, while also fostering his independence as appropriate. One option which parents may wish to consider is guardianship, which gives the designated guardian the legal right to make certain decisions on behalf of the adult child. It is important to realize that each person with autism is a unique individual, and therefore there is no one “right” answer that fits every situation. This guide is intended to provide parents with practical information about guardianship to help them make an informed decision.

This article is not intended to be a substitute for legal advice, and parents are urged to contact a special needs attorney to discuss the specifics of their family's situation. Only an attorney can provide legal advice about guardianship.

### Basic Facts to Consider As Your Child with Autism Becomes an Adult

- At the age of 18, a child is legally considered to be an adult.
- The parents are no longer the legal guardians once the child reaches the age of majority.
- Adult children may need the protection of a guardian if they cannot care for themselves, make decisions in their own best interests, or manage their financial assets.
- Guardianship should not be automatic; not all individuals with Autism Spectrum Disorder (ASD) require the protection of a guardian.
- Consider the strengths, weaknesses, needs, and best interests of the individual before making the decision to seek guardianship.

### What Is Guardianship?

[The North Carolina Division of Aging and Adult Services](#) defines guardianship as “a legal relationship in which someone (the guardian) is authorized by the clerk of superior court to be a substitute decision maker for an incompetent adult (the ward). Incompetence is determined in a court proceeding and means an adult is unable to manage his own affairs, or is unable to make important decisions.” Laws defining the powers and responsibilities of a guardian can be found in the [North Carolina General Statutes Chapter 35A](#).

In other words, guardianship is a legal process in which the guardian is given the authority to make decisions on behalf of their ward (in this case, their adult child). A guardian is often a parent, but not always. The decisions the guardian has the power to make will depend on the type of guardianship, which is discussed in greater detail below.

### **When Is Guardianship Needed?**

According to North Carolina law, guardianship is appropriate when an adult, an emancipated minor, or a minor who is at least 17 1/2 years of age, who other than by reason of minority, *lacks sufficient capacity to manage his affairs or to make or communicate important decisions concerning himself, family, or property*, whether the lack of capacity is due to mental illness, mental retardation, epilepsy, cerebral palsy, autism, inebriety, senility, disease, injury, or similar cause. (N.C. Gen. Stat. 35A-1101)

These are the general reasons why a person might need a legal guardian to protect their interests and ensure their care:

- A minor is approaching the age of 18 and will be considered an incompetent adult.
- A minor inherits property and needs a guardian to manage it.
- A minor loses their parent (s) and needs a guardian to make personal decisions.
- An adult becomes incompetent through injury, illness, or disease and needs a guardian to make personal, health care, end of life, or property decisions on their behalf.

The primary focus of this article is on individuals with autism who are approaching the age of 18 or adults with ASD who may need a guardian.

Incompetence is a legal, not a medical term, and it is defined in greater detail below. Remember that not all adults with autism will need guardianship; we will briefly cover some alternatives to guardianship later in this article. An attorney can provide you with more details about the different avenues parents can take to protect the interests of their adult children.

### **What Are the Responsibilities of a Guardian?**

A guardian has several general responsibilities, as well as more specific ones, depending on the type of guardianship. The primary role of a guardian is to protect the welfare of their ward, while also helping them to exercise their rights. Guardians may be responsible for management of the ward's finances, property, health care, and other personal affairs. It is the responsibility of the guardian to:

- Make major decisions on behalf of their ward.
- Act in the best interest of the ward.
- Allow the ward as much freedom to participate in the decision making process as they can handle. This may include allowing the ward to make some less-than-ideal decisions, as long as they will not cause harm to the ward or his estate.
- Veto poor decisions made by the ward.

A guardian is **not** responsible for financially supporting their ward, nor are they liable for the ward's debts. In addition, the guardian is not required to have the ward live in their home.

## **Types of Guardians**

In the state of North Carolina, there are three types of guardianship. The appropriate type for your family's situation will depend on the strengths and challenges of your child. A special needs attorney may be able to guide you in deciding which type of guardianship would be best for your family.

**Guardian of the Person:** The guardian of the person is responsible for monitoring the care of the ward. It is their job to ensure that their ward receives proper care and supervision, medical care, education, and vocational assistance or training. Consider this type of guardianship if your child is unable to manage their own daily living responsibilities. The guardian usually files an annual report to the court. As a guardian of the person, your responsibilities include:

- Determining where your ward will live. This decision should be based on the preferences, needs, and resources of the ward, with as much input from them as is practical. The state requires that community based living situations be given preference over institutional settings.
- Ensuring that the ward receives good care. This includes arranging for training, education, employment, and rehabilitation.
- Giving consent or approval for needed services, such as medical, dental, legal, or psychological.
- Taking reasonable care of the ward's belongings.
- Taking legal action to protect the ward if needed.

**Guardian of the Estate:** The guardian of the estate is responsible for managing the ward's income and property. This is essential in instances where your adult child is not yet able to consistently manage their finances. Parents may wish to become guardians of the estate if they are concerned that their child is vulnerable to being taken advantage of financially. It may also be advisable if the child is not prepared to manage daily living expenses. Of particular consideration is the fact that an individual who receives certain government benefits like Supplemental Security Income (SSI) or Medicaid may have to keep their assets and accounts below certain levels to retain eligibility. The guardian of the estate can monitor and "spend down" accounts on behalf of their ward as needed to ensure compliance with government requirements. It is important for a guardian of the estate to keep detailed records of income and expenditures, as they must file an annual accounting of the ward's funds with the court. General responsibilities of the guardian of the estate include:

- Managing the ward's income and property, including spending down accounts as needed.
- Making financial decisions on behalf of the ward, with their input as appropriate. If you hope that your child will one day be able to manage their own resources, it is important to educate them about how to handle their money and property. Guardianship allows you the opportunity to teach your adult child about making sound financial decisions while still protecting their assets.
- Keeping detailed records and making an annual account to the clerk of the Superior Court about the ward's assets and all expenditures made from their account.

- Obtaining prior approval from the court for certain transactions such as the sale or lease of the ward's property.

**General Guardian:** This type of guardianship combines the responsibilities of the Guardian of the Person and the Guardian of the Estate. General guardianship might be appropriate if you feel that your adult child is not prepared to manage their personal affairs or their finances. Keep in mind that as a guardian, you have the option of allowing your ward increasing freedom to make their own decisions as you feel that they are ready.

### **Deciding Between Joint or Individual Guardianship**

If you decide to seek guardianship for your adult child, you will need to decide between joint or individual guardianship. It is very important to understand that in situations where decisions must be made on behalf of the ward, joint guardianship requires the agreement and consent of **both** guardians, not just either guardian. Parents may find it more practical to pursue individual guardianship, as then only one of them would be required to sign papers, give consent for medical treatment, and the like. If the parents of the adult child with autism are accustomed to making joint decisions regarding their care, individual guardianship does not preclude having family discussions before making decisions, it simply means that only one parent is required to give formal consent.

### **Choosing a Guardian**

For those parents who determine that guardianship is the right choice for their adult child with autism, there is no more important decision than choosing their guardian. It is often one or both parents (in the case of joint guardianship) who will apply to be the guardian for their child. Typically, the parent who was already the primary caregiver for the child will become his guardian. Another consideration is which parent will be more available to take action on behalf of their child. For instance, who would be more readily available if urgent consent was needed for medical treatment or if papers needed to be signed?

While parents often wish to be their child's guardian, in some cases, another person might be better suited to serve in that role. Elderly parents, for example, might ask one of their adult children to serve as the guardian for their child with autism. If parents or siblings are not going to be the guardian, a relative or very close friend of the family might be another option. Given the high level of trust you need to have in your child's guardian, this is a decision that should be weighed very carefully.

### **What If a Guardian Dies or Lives Out of State?**

When a parent becomes the legal guardian of their child, they can select a “guardian successor” in their will. Should the original guardian die, the clerk of the court would then determine if the recommended person is a suitable guardian using the same criteria by which the initial guardian had been approved. For some parents, this may ease their minds if they opt against joint guardianship.

Parents may wonder whether committing to be their child's guardian means that they can never move out of state. It is possible for a non-resident to serve as guardian to a person who lives in North

Carolina, as long as they follow certain steps. Essentially, the non-resident guardian must agree in writing to submit to the jurisdiction of the North Carolina courts in matters relating to the guardianship. In addition, they must appoint a resident agent, who needs to be approved by the clerk. Finally, if you live out of state, you will be required to post a bond or other security for the faithful performance of duties as a General Guardian or Guardian of the Estate. A non-resident Guardian of the Person may be required to post a bond as well.

## **The Guardianship Process**

Guardianship is a legal process with defined steps to follow. More details are available on the [NC Division of Aging and Adult Services](#) website. You may begin the process when your child is at least 17 ½ years old. The person filing a petition to begin the application is referred to as the petitioner, and the person over whom guardianship is sought is called the respondent. If guardianship is approved by the court, the person who takes responsibility is called the guardian, and their adult child is called their ward.

These are the steps in the guardianship process:

- The parent (or any concerned individual) files a petition with the clerk of the Superior Court in their county alleging that an adult (the respondent) should be declared incompetent and have a guardian appointed. Forms are available in the county courthouse or online at <http://www.nccourts.org/Forms/Documents/707.pdf>. The clerk will set a date for a hearing.
- The sheriff will serve the petition and the notice of the hearing on the respondent.
- The court will appoint a Guardian ad Litem, who is an attorney that represents the respondent (in this case, the adult with autism) and ensures that their best interests are being considered throughout the proceedings.
- The Guardian ad Litem will meet with your child to determine their needs and wishes. The petitioner should present the Guardian ad Litem with information showing why they believe their child is incompetent and needs a guardian. This could include reports from therapists, doctors, teachers, or others who know your child well. The court clerk may also order evaluations to help determine whether the respondent is incompetent. You may request a written report of the results.
- You can ask the Guardian ad Litem to share with you whether they will recommend guardianship or not. If they intend to recommend in favor of it and your child is accepting of guardianship, the hearing can be a fairly routine process. However, if either the Guardian ad Litem or the respondent (your child) does not support your petition for guardianship, the process can become adversarial, involving Rules of Evidence and Rules of Civil Procedure. The petitioner will have the burden of proving incompetency through expert testimony. An attorney would be strongly recommended in that situation.
- The actual guardianship hearing can take place in a courtroom or in a conference room in the courthouse, if the petition is uncontested. At the conclusion of the hearing, the court will either determine that the respondent is incompetent and needs a guardian or the court can decide that the respondent is a competent adult and dismiss the petition. If incompetency is determined, the clerk will then hear evidence about who should be appointed the guardian.

- Once appointed, the guardian will take an oath and post a bond if necessary. He will then be presented with the Letters of Guardianship, which are the documents giving him authority to act on behalf of his ward. Guardians should keep the Letters of Guardianship handy, as they may need to be presented to doctors, schools, financial institutions, and care providers.

### **Preparing Yourself and Your Child for the Guardianship Process**

Approaching the issue of guardianship can be difficult for parents. It can be an emotionally charged time, because filing a petition for guardianship means facing the fact that your son or daughter is not ready to become an independent adult at age 18. It may mean adjusting your dreams for your child, and forming a new vision of what a good life will look like for them. Parents often struggle with applying the term “incompetent” to their young adult, who undoubtedly is competent and able in many ways. Here are some suggestions that may help parents become comfortable with the concept of guardianship:

- Remind yourself that by making an informed decision to seek guardianship, you are showing your love for your child by ensuring their future protection.
- Speak to other parents who have obtained guardianship over their adult children with autism. Your [local ASNC Chapter](#) can be a good place to connect with families who have been through this process.
- Consult with those who know your child well and seek their opinions on how likely he would be able to function independently without the oversight of a guardian.
- Remember that the term “incompetent” as it applies to guardianship is a legal term, not a judgment.
- Keep in mind that guardianship may be reversed if at some time in the future your adult child shows he is ready for more independence.
- Talk to your child about guardianship – he may actually be relieved to know that his parents will still be looking out for him even after he turns 18.

It is equally important to prepare your child for guardianship. Their reactions can vary considerably, but there is much that parents can do to help the process go as smoothly as possible. As parents, you know your child better than anyone, and you will have the best sense of how much information to share and what approach is most likely to be well received. These are some ideas of how to make the process of guardianship as stress-free for your young adult with ASD as possible:

- Many individuals with autism prefer consistency and continuity in their lives. Your child might be glad to hear that with guardianship, there will be no dramatic changes in their day-to-day life when they turn 18.
- Assure your child that you will seek his input into the decisions you make that affect his life.
- Let your child know (if appropriate) that guardianship is not always forever.
- If your child is upset by the term “incompetence”, explain that it simply means that he could use your continued help making decisions, not that you do not think of him as a capable person.

Your young adult also needs to be prepared for the procedures surrounding the petition for guardianship. He will come into contact with several new people, and it may help to explain the role of each person he will be meeting. Social Stories and/or role playing may be useful in preparing your child for what to expect. Those involved will usually do everything they can to make the guardianship process as easy as they can for the respondent. For instance, the Guardian ad Litem can come to your home to meet with your child if that would be more comfortable for him than going to an appointment in an office. You can also offer your child the choice of attending the hearing or staying home.

**Tip:** The most anxiety-provoking part of the guardianship process for some individuals with ASD is being presented with the petition by the sheriff. If your child has had previous interactions with law enforcement, they may need assurance that the sheriff's presence does not mean that they have done something wrong. Some respondents find it less stressful to have the sheriff drop off the papers at home. If you make this arrangement, you may wish to inform your neighbors in advance that you are expecting the sheriff so they are not concerned. For other young adults, it might be less threatening to have the sheriff give them the petition while on a “tour” of the sheriff's office. Most sheriffs will accommodate reasonable requests like these.

### **What Is Legal Incompetence?**

At the heart of the matter of guardianship is determining whether or not an adult is legally incompetent, meaning that he is unable to “manage his affairs or to make or communicate important decisions concerning himself, family, or property.” The law presumes that adults are competent, unless proved otherwise. The process of guardianship seeks to prove that this is not the case for the respondent. For individuals with autism, the ability to effectively communicate may be especially important to consider, as are daily living skills, and vulnerability due to reduced capacity to understand social cues (ie, to see when someone may be planning to take advantage of them).

Keep in mind that adults have the freedom to make bad decisions, and that having a disability like autism does not equal incompetence. Parents with legally competent adult children will surely report that their offspring do not always make the best decisions either. It is also important to note that incompetence in one area does not mean incompetence across all domains. That is why the state offers the more limited forms of guardianship, the Guardianship of the Person and the Guardianship of the Estate.

### **Rights Lost By an Incompetent Adult**

When an adult is found to be incompetent, they lose certain rights. These include:

- The right to self-determination
- The right to serve on a jury
- The DMV may deny the privilege to drive

## **Rights Which May Be Retained By an Incompetent Adult**

Certain legal rights may be retained by an incompetent adult. The rights which are retained by an incompetent adult will vary depending on the particular situation, and may include:

- The right to vote
- The right to enter into a contract, including marriage. This would depend on whether or not the ward has sufficient capacity to understand the nature of the contract and its consequences.
- The right to make a will. The individual will be presumed to be incompetent in this matter, but sometimes they may rebut that presumption.
- The right to drive. This is determined by the DMV.
- The right to be a witness. To be a witness, the ward must be able to understand an oath, telling the truth, consequences of perjury, and have the capacity to observe, remember, and relate events.

## **The Guardianship Capacity Questionnaire**

[The Guardianship Capacity Questionnaire](#) is designed to help those considering guardianship. It was developed to promote limited guardianship for those who may have limited capacity in some life areas while retaining functional capacity in other areas. The Guardianship Capacity Questionnaire also seeks to identify situations where alternatives to guardianship might be appropriate. Think of it as a continuum, with full legal competency on one end and General Guardianship at the other end. In between are options such as a power of attorney, limited guardianship, or guardianship of only the estate or the person. In other words, the state prefers for adults to retain as many of their rights as they can safely manage, therefore less restrictive alternatives should be considered before General Guardianship.

The questions on the Guardianship Capacity Questionnaire are divided into 10 life domains. The intent of the questions is to gather information that will be useful to all of those involved in the guardianship process, including the petitioner, the respondent, and the Clerk of the Court. The interviewer can pose the questions to at least two or three different people, one of whom should be the respondent.

The 10 life domains addressed in the Guardianship Capacity Questionnaire are:

1. Language and Communication
2. Nutrition
3. Personal Hygiene
4. Health Care
5. Personal Safety
6. Residential
7. Employment
8. Independent Living
9. Civil
10. Financial

A complete copy of the Guardianship Capacity Questionnaire is available to view and download at <http://www.nccourts.org/forms/Documents/846.pdf>.

### **Can Guardianship Be Reversed or Modified?**

Yes, in some instances guardianship can be reversed or modified. If you feel at some point that your adult child with ASD is now able to manage some or all of their personal and financial decisions, you can petition the court to either modify or terminate the guardianship. Terminating the guardianship requires a motion for [Restoration of Competency](#) to be filed with the court. Your child, as the ward, also has the right to submit a motion to be restored to competency. Evidence must be presented to show that the ward can now manage his own affairs. If the Clerk or a jury finds that the ward has sufficient capacity to manage his or her own affairs and to make and communicate important decisions regarding his or her person, family, and property, the Clerk will enter an order restoring the ward to competency. However, it is not always easy to restore competency, and some Clerks may be reluctant to do so.

Sometimes the situation may call for the guardianship to be modified. The terms of the guardianship can be changed to allow exercise of additional rights or to restrict the exercise of certain rights. The type of guardianship can also be modified. However, the person who is filling the role of the guardian cannot be modified. The guardian will only be changed if they resign, are removed for cause, or die. This is why it is extremely important to choose your child's guardian with great care.

### **Alternatives to Guardianship**

There are instances in which your adult child with autism may need certain protections, but not guardianship. Just like any adult, the individual with ASD has the right to self-determination to the fullest extent possible. It is worthwhile to explore less restrictive alternatives to guardianship to see if one (or a combination) might be suitable. You may need to consult with an attorney, tax adviser, or banker to determine which of these can serve your purposes. Parents should also make sure they clearly understand any potential liability which may result from financial arrangements they set up for their child; ie, if your child overdraws a joint bank account, will you be equally responsible for the debt? Some of the alternatives to guardianship include:

- **Joint bank account with automatic deposits and a permanent withdrawal rider.** This will allow you to help your son or daughter manage their money. You can arrange for benefit checks or other income to be directly deposited into their account. A permanent withdrawal rider is an arrangement you make with the bank for recurring transfer of funds out of the account, such as a monthly rent payment.
- **Power of Attorney.** Establishing a power of attorney is far simpler than the guardianship process. It gives the agent (such as the parent) the power to make decisions and take actions on behalf of the principal (your child). The financial power of attorney permits the agent to do things like pay bills or manage bank accounts for their child, while the healthcare power of attorney allows the agent to make medical decisions. In some instances, the more limited

scope of a power of attorney may be a suitable substitute for guardianship of the estate or guardianship of the person. However, you should be aware that your child has the right to withdraw the power of attorney at any time. Additionally, even with a power of attorney in effect, the principal is still able to legally make important decisions, including committing to binding contracts.

- **Representative payee.** If your adult child with ASD receives government benefits like Supplemental Security Income (SSI), it is possible to become a [representative payee](#) for their account. The representative payee uses the individual's benefits to pay for their current and foreseeable needs, while responsibly saving the surplus. It is important that the representative payee keep good records of how they have spent the beneficiary's funds.
- **Special needs trust.** This is a type of trust which is specifically designed for people with disabilities. The trust is drafted to provide services and funds for needs that are not met by government benefits. It will comply with the rules of needs-based benefits such as SSI, Medicaid, Section 8 Housing and Food Stamps. Special needs trusts are extremely complex, and must be drafted by an attorney who specializes in estate planning. They must also be administered with great care so as not to affect the child's eligibility for government benefits.
- **Case management and advocacy services.** Your adult child with autism may be eligible to receive case management and advocacy services that can help him to navigate his world with greater independence than guardianship allows. An [ASNC Parent Advocate](#) can also help direct you to resources in your area.
- **Limited Guardianship.** During guardianship proceedings, the Clerk has the option to implement a limited guardianship, in which the ward retains more powers than in a standard Guardianship of the Person, Guardianship of the Estate, or General Guardianship. The Letters of Guardianship will spell out precisely which powers the guardian has, and they should be based upon the specific needs of the ward. For example, if a young adult with autism can handle basic finances but not more complex financial matters, the Guardianship of the Estate could be modified to allow them control of certain monies to meet their daily needs (buying groceries and so on). The Guardianship Capacity Questionnaire can be helpful in determining areas of strength and concern that need to be addressed by the Limited Guardianship.

## **Resources and Information about Guardianship and Alternatives**

The Autism Society of North Carolina has 16 [Parent Advocates](#) and one Hispanic Affairs Liaison who are available to provide information and direct families to resources in their community. Parent Advocates also offer [workshops](#) about the guardianship process.

The Autism Society of North Carolina has approximately [50 local Chapters](#) and support groups across the state that allow parents to share experiences, information, and resources.

[The North Carolina Division of Aging and Adult Services](#) provides an overview of the guardianship process in North Carolina.

Guardianship forms are available at [www.nccourts.org](http://www.nccourts.org). In the “Forms” section you will find important forms, including AOC-SP-200 “Petition for Adjudication of Incompetence and Appointment of a Guardian,” the form used to begin the guardianship process, and AOC-SP-208, the “Guardianship Capacity Questionnaire.”

The “Responsibilities of Guardians in North Carolina” booklet is published by the North Carolina Administrative Office of the Courts.

**North Carolina Guardianship Association:** A non-profit providing advocacy, education, leadership, training, technical assistance, and networking for guardians, consumers, family members, volunteers, professionals, and surrogates.

**National Guardianship Association, Inc.:** A national organization promoting excellence in and education about guardianship. Their website has a lot of basic information about guardianship that may be useful to parents.

**Life Plan Trust** is a Service Program of the Autism Society of North Carolina, The Arc of North Carolina, NAMI North Carolina, and Easter Seals UCP of North Carolina whose mission is to provide information on future planning for families of people with disabilities. Their publication, *Estate Planning for Families of Persons with Disabilities 5th Edition*, discusses wills, trusts and guardianship to assist parents in planning for the future.

**The Arc of North Carolina**, an affiliated chapter of The Arc of the United States, is an organization that serves individuals with intellectual or developmental disabilities. They offer a broad range of services related to guardianship and future planning.

**First in Families of North Carolina Lifetime Connections Program** offers seminars on planning for a safe and secure future for your loved one with a disability. Topics covered include wills, estate planning, building a support network, ensuring choices, and securing your plans.